

Staffordshire

Autism Joint Implementation Plan

2020-2023

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Introduction

1. Autism is a lifelong developmental disability that can significantly impact the lives of people living with it. Autism affects individuals in a variety of ways and can affect their ability to live an independent life to varying degrees. It is a spectrum condition, which means that while all people with Autism share certain areas of difficulty, their condition will affect them in different ways.
2. Autism is not a Mental Health condition or a Learning Disability. However, around half of people with Autism have a Learning Disability and three quarters are likely to have a Mental Health condition at some point during their lives¹. This Plan therefore also applies to people with Autism with these additional needs, so that meaningful and seamless pathways to care are available.
3. The **Staffordshire Whole Life Disability Strategy**² set out a vision to ensure that people with any disability:
 - Are able to do things for themselves as much as they can with a focus on ability rather than disability.
 - Are as independent as they can be for as long as they can
 - Use what is available in their communities first rather than using paid for services.
4. The Strategy committed to developing a series of Plans to achieve this vision. This Plan is part of that approach. It has been informed by legislation and national policy, an assessment of local needs and engagement with people with lived experience of Autism.
5. Many people with Autism can and do live independently if reasonable adjustments are applied to universal services. This Plan aims to encourage all services and organisations to “think autism” and maximise opportunities to help people with autism in Staffordshire to live fulfilling lives and feel part of society.
6. A relatively small number of people with Autism are eligible for additional care and support - often due to a concurrent Learning Disability or Mental Health condition. With an ongoing financial challenge across public services, this Plan aims to bring together the organisations that fund and provide care and support and redesign services so that they can continue to meet people’s needs and make best use of resources. People with autism, their families and carers will be able to influence and shape the way that services are designed and provided³.

¹ NICE has made recommendations about the delivery of care to children and young people on the autism spectrum. This includes a recommendation that local services should work with and support the families of children and young people on the autism spectrum. It also recommends that local services should be coordinated by a local autism multi-agency strategy group.

² Whole Life Disability Strategy: [Whole-Life-Disability-Strategy-2018-2023](#)

³ Source: National Autistic Society UK

Legislation and National Policy

7. The **Autism Act (2009)** places a duty on all Local Authorities to produce an Autism strategy. This Plan fulfils that duty in Staffordshire and is written with due regard to relevant UK legislation and statutory guidance.
8. The Government's **Think Autism Strategy (2014)**⁴ provides a clear vision for improving lives of individuals with Autism:
'All children and adults with autism are able to live fulfilling and rewarding lives within a society that accepts them and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream services to treat them fairly as individuals, helping them make most of their talents.'
9. The Strategy, and the subsequent *'Statutory Guidance for Local Authorities and NHS organisations'* in March 2015 (updated 2018), have provided further detail on what improvements need to take place. The Government identified five domains for national action (Appendix 1) as well as 15 priorities for local action, which were presented as "I Statements", and which form the basis for this Plan.
10. The **NHS Long Term Plan** identifies that the NHS has a crucial role to play in helping people with Autism, a Learning Disability or both, lead longer, happier and healthier lives, and:
'aims to improve people's health by making sure they receive timely and appropriate health checks, while improving the level of awareness and understanding across the NHS of how best to support them as patients'
11. In this Plan the NHS commits to:
 - Develop a clearer, more widespread focus on the needs of Autistic people and their families, starting with children with the most complex needs;
 - Improve community-based support so that people can live in their own homes rather than specialist hospitals;
 - Ensure that NHS services offer good quality care to people with a Learning Disability and Autism and their families by making reasonable adjustments so that they can enjoy equal access to and outcomes from treatment;
 - Reduce health inequalities, improving uptake of annual health checks, reducing over-medication and taking action to prevent avoidable deaths;
 - Champion the insight and strengths of people with lived experience and become a model employer of people with a Learning Disability and Autism;

⁴ <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

- Ensure the whole NHS has an awareness of the needs of people with a Learning Disability and Autism, working together to improve the way it cares, supports, listens to, works with and improves the health and well-being of them and their families

Local Needs

12. There are currently 331 individuals with Autism known to Staffordshire adult social care services, with 211 of those currently in receipt of a service. There are currently 1,377 children and young people, with a primary need of Autism, with an Education Health and Care Plan (EHCP) of which 180 are in receipt of a social care service. Approximately 2000 children and young people are known to the Autism Outreach Team.
13. Further details are presented in Appendix 2. Further work will be carried out in 2020 to develop a more thorough understanding of the needs of people with Autism, including a review of any future Joint Strategic Needs Assessment programme.
14. Staffordshire's health and social care system has made some progress since 2018 in developing diagnostic pathways and services for people with Autism. There are now Autism assessment and diagnostic services for children, young people and adults living in Staffordshire. This was a key requirement within the original '*Fulfilling and Rewarding Lives*' strategy and its associated statutory guidance.
15. Following a diagnosis, a range of care and support is available:
 - Voluntary sector organisations provide a range of services for people with Autism and their families including support, advice and specialist help. Information about these groups can be found on Staffordshire Connects⁵.
 - Children and young people typically access support through educational settings. Schools and other educational settings are required to make reasonable adjustments to facilitate the inclusion of children and young people with autism. The Autism Outreach Team provide support to schools and educational settings based around materials accredited by the Autism Education Trust. They also provide specific guidance and bespoke packages of support.
 - Children and young people with the most complex needs may require an Education, Health and Care Needs Assessment. This will enable additional support to be made available to meet needs when necessary. Families and professionals can request a needs assessment through the local authority.

⁵ <https://www.staffordshireconnects.info/kb5/staffordshire/directory/home.page>

- For those children and young people with Autism, and their families, likely to require additional social care support once they turn 18 years of age, a referral will be made to the appropriate adult social care service as part of Preparation for Adulthood at school year 9 (age 14) at the latest. They will then receive an assessment to determine any eligibility within their 16th year.

Engagement Feedback

16. The Council held a range of engagement activities to inform development of the Whole Life Disability Strategy. Further engagement activities specific to Autism were held by the Council and Clinical Commissioning Groups (CCG) during September and October 2019, to support development of this Plan. The main themes emerging are highlighted below with further details available on the Council's website⁶.
17. Of the 15 "I Statements", feedback was that the priorities were:
 - I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process;
 - I want to know that my family can get help and support when they need it;
 - I want staff in health and social care services to understand that I have Autism and how that affects me;
 - I want services and commissioners to understand how my Autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies;
 - I want Autism to be included in Local Strategic Needs Assessments so that person-centred local health, care and support services, based on good information about local needs, are available for people with Autism
18. Engagement also identified the following key themes:
 - A need for more consistent training and awareness of Autism across all services and staff working in those services;
 - A need to ensure that there are adequate diagnostic services
 - A need for increased communication and sharing of information, across all professionals, to prevent individuals having to repeatedly tell their story;
 - A need for clear advice, guidance and signposting, from staff that understand Autism, to the support available in local communities;
 - A need to ensure sufficient capacity and quality of support available;
 - A need to focus on an individual's health and well-being, not their diagnosis.

⁶ <https://www.staffordshire.gov.uk/Care-for-all-ages/Whole-life-disability-strategy/Implementation-plans-Autism.aspx>

Outline of the Plan

19. The Council and CCGs aspire to develop a society that is Autism friendly, which values and supports those with Autism, and their family and/or carers, to maintain their health and wellbeing. Therefore, we have placed emphasis on prevention to avoid, reduce or delay dependency on health and social care services by increasing the resilience of individuals and communities.
20. The Council and CCGs will support the ongoing development of communities to ensure a credible local offer for those individuals with Autism, and their family and/or carers. We will support local communities to develop to be strong and inclusive, be sustainable and support individuals with Autism, and their family and/or carers, to help themselves, enabling us to target our resources for those who are most in need of support.
21. The Council and CCGs will ensure that people understand their entitlement to and the benefits of, an assessment and routinely offer one on the appearance of need. Where an assessment identifies care and support needs, we will look to meet those needs with support from their local community in the first instance, avoiding the need for paid for services wherever possible.
22. The Council and CCGs will adopt a whole family approach to system wide assessments, with professionals working together so that the needs of people with Autism, and their family and carers, are identified and responded to appropriately.
23. The Council and CCGs will ensure that staff who undertake assessments, across the wider system, have the appropriate skills, knowledge, competence and training to do so and that they fully involve the individual being assessed if that is what they wish (taking into account their capacity to consent). Where required, access to an independent advocate will be provided.
24. The Council and CCGs will ensure that system wide assessment information is recorded in a timely way, making sure it is comprehensive, accurate, stored safely and shared accordingly to the standards required under data protection legislation so that the need for individuals to repeat their story is kept to a minimum.
25. The Council and CCGs will help those with Autism and their families/carers who are eligible to receive support. We will ensure that they receive the right support, at the right time, and develop plans to help reduce or delay longer term support needs. We will do this in a way which is safe and financially sustainable.
26. The Council and CCGs will work in partnership with people with Autism and their family/carers, as well as a range of organisations across the public sector

(including NHS Trusts, Department for Work and Pensions, Housing, Education and the Police); private sector (such as providers of care and support); and the voluntary and community sector, to support individuals with Autism and their family/carers’.

27. The full Joint Implementation Plan is included at Appendix 3.

Implementation and governance

28. We will establish an Autism Joint Implementation Group, including people with lived experience, that will oversee implementation of the Plan.

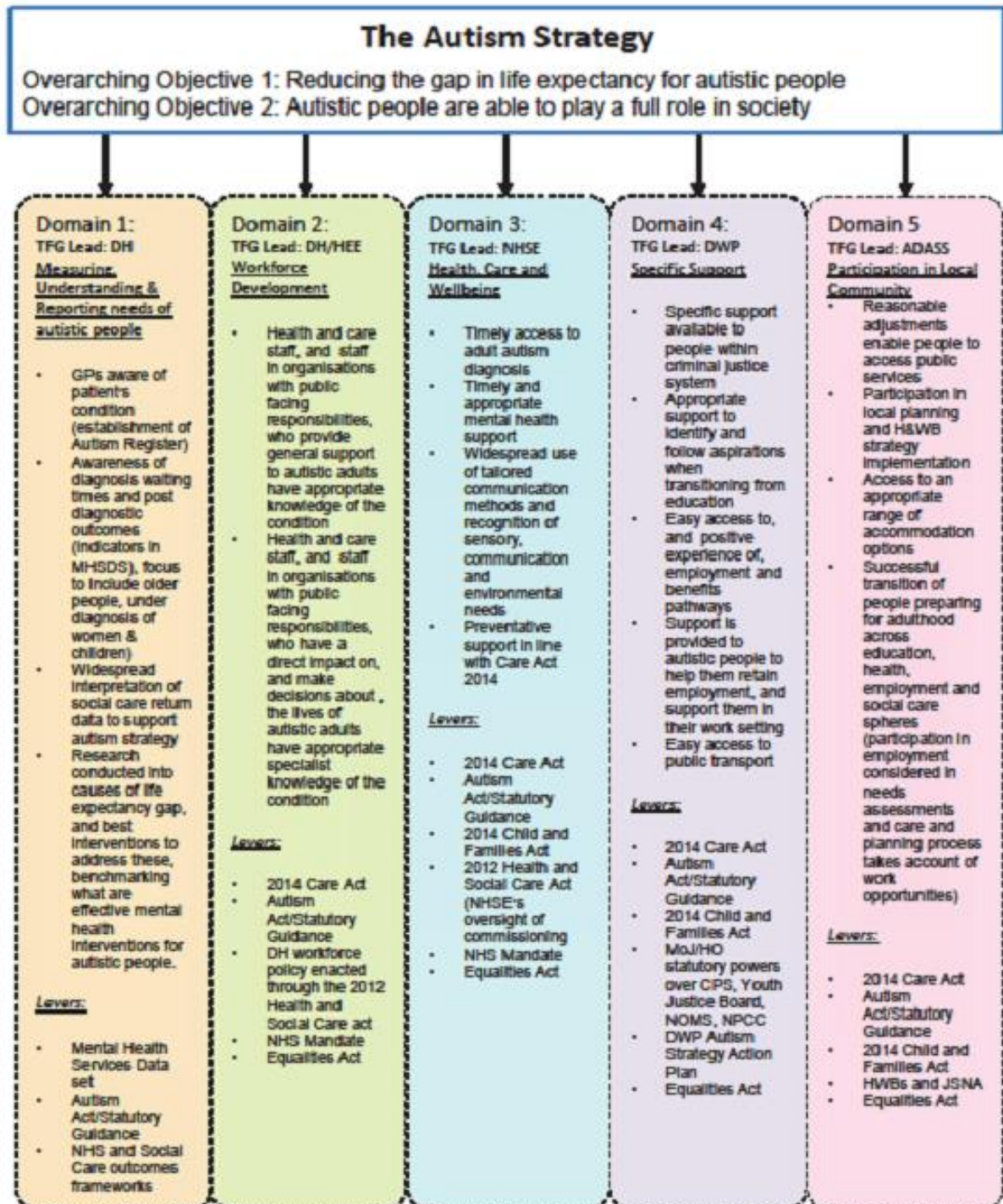
29. The Group will use the Plan as a basis to continue engagement with people with Autism to get their views about prioritising and making changes to local services.

30. The Group will also engage with:

- NHS Trusts
- Department for Work and Pensions
- Criminal Justice Services
- District and Borough Councils
- NHS and social care team and professionals
- Specialist and independent providers of services
- Education providers
- Commissioners

31. The Group will monitor delivery of the Plan and take into account feedback from people with Autism and the families/carers as well as these other organisations. The Group will produce annual report on progress and achievements.

Appendix 1: five domains for national action



Appendix 2: Outline Needs Assessment




Children and young people

32. The total number of children and young people identified with ASD at school in Staffordshire was 2000 in 2019. The number of children and young people with Autism known to schools is shown in Figure 1 with figures per 1,000 pupils. There are more children and young people identified than in comparator authorities.

Figure 1: children and young people identified with Autism at school per 1,000 pupils

Area	Value	Lower CI	Upper CI
England	12.5	12.4	12.6
West Midlands region	12.8	12.6	13.0
Birmingham	17.7	17.2	18.3
Coventry	21.5	20.4	22.7
Dudley	9.1	8.3	10.0
Herefordshire	8.1	7.1	9.3
Sandwell	5.5	4.9	6.1
Shropshire	6.0	5.3	6.7
Solihull	23.7	22.2	25.2
Staffordshire	14.0	13.4	14.7
Stoke-on-Trent	6.6	5.8	7.4
Telford and Wrekin	10.3	9.2	11.5
Walsall	8.6	7.9	9.4
Warwickshire	13.1	12.3	13.8
Wolverhampton	5.3	4.7	6.1
Worcestershire	9.6	9.0	10.3

Source: Department for Education statistical collections: Special Educational Needs, local authority tables
<https://www.gov.uk/government/collections/statistics-special-educational-needs-sen>

Average 
 Below Average 
 Above average 

33. The report Prevalence of Disorders of the Autism Spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)⁷, found that 55% of those with ASD have an IQ below 70

⁷ Baird, G. et al, The Lancet, 368 (9531), pp. 210-215, 2006

Adults

34. Nationally, as well as locally, there is limited data relating to Autism. National figures⁸ are published about people with disabilities including people with Autism. The information below is based on a Report from the Adult Psychiatric Morbidity Survey 2007, published by the Health and Social Care Information Centre in September 2009.
35. The prevalence of Autistic Spectrum Disorder (ASD) is 1.0% of the adult population in England, using the threshold of a score of 10 on the Autism Diagnostic Observation Schedule to indicate a positive case. The prevalence among men (1.8%) is higher than that among women (0.2%), which fits with the profile found in childhood population studies.
36. These prevalence rates have been applied to ONS population projections of the 18+ population to give estimated numbers of people with ASD in Staffordshire (Table 1).

Table 1: People aged 18+ predicted to have ASD, projected to 2035					
	2019	2020	2025	2030	2035
Males aged 18-24	632	617	592	643	646
Males aged 25-34	961	961	943	878	887
Males aged 35-44	889	895	956	999	983
Males aged 45-54	1,136	1,112	967	929	990
Males aged 55-64	1,042	1,064	1,147	1,091	961
Males aged 65+	1,607	1,631	1,771	1,955	2,111
Total Males	6,267	6,280	6,376	6,495	6,578
Females aged 18-24	61	59	58	63	63
Females aged 25-34	100	100	96	89	91
Females aged 35-44	100	101	106	108	104
Females aged 45-54	127	124	109	105	111
Females aged 55-64	118	121	129	123	109
Females aged 65+	206	209	225	246	264
Total females	712	714	723	734	742

37. Some very able people with ASD may never come to the attention of services as having special needs, because they have learned strategies to overcome

⁸ <https://www.pansi.org.uk> and <https://www.poppi.org.uk/>

any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents.

38. Other people with ASD may be able intellectually, but have need of support from services, because the degree of impairment they have of social interaction hampers their chances of employment and achieving independence.
39. The National Autistic Society⁹ states that 'estimates of the proportion of people with Autism Spectrum Disorders (ASD) who have a Learning Disability, (IQ less than 70) vary considerably.
40. The problems people with Autism have in understanding social interactions, having sensory acuity that can easily lead to overwhelming anxiety and reaction and other associated issues, can mean that they become involved with criminal justice agencies because of their disability rather than through intention or be subject to bullying or harassment.
41. People with Autism require equal accessibility to physical and mental health services to ensure that any such additional needs are identified and supported within the appropriate service.

⁹ <https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx>

Appendix 3: Joint Implementation Plan

Outcomes to be achieved	Actions			
	Priority	By April 2021	By April 2022	Longer term
1. An equal part of my local community				
<ul style="list-style-type: none"> I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of Autism 		Availability of awareness raising and establish and promote relevant information links on LA and CCG Websites	Wider awareness raising across public, private and voluntary sectors	
<ul style="list-style-type: none"> I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others 		Membership of Autism Implementation Group to include people with Autism and their support networks	Engagement in Health and Well Being processes	Benchmarking information with other LAs and CCGs
<ul style="list-style-type: none"> I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low-level support 		Autism Implementation Group to review information available through Staffordshire Connects and CCG equivalent websites	Further refine links following Information Advice and Guidance review	Work to promote and support an increase in appropriate groups in local communities
<ul style="list-style-type: none"> I want everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want staff who work in them to be aware and accepting of Autism 		Autism Implementation Group to agree to awareness raising programmes for statutory services	Autism Implementation Group to agree and progress how we better engage and involve Private Sector	Look to establish and embed "Autism Friendly" kite mark
		Awareness raising and information for all public services	Autism Implementation Group to develop plan for wider employer awareness raising	
<ul style="list-style-type: none"> I want to be safe in my community and free from the risk of discrimination, hate crime and abuse 		Autism Implementation Group to include representation from Law Enforcement agencies	Autism specific Hate Crime and Abuse report for local areas	

<ul style="list-style-type: none"> I want to be seen as me and for my gender, sexual orientation and race to be considered 		Equalities review of current service delivery		
Outcomes to be achieved	Actions			
	Priority	By April 2021	By April 2022	Longer term
2. The right support at the right time during my lifetime				
<ul style="list-style-type: none"> I want Autism to be included in the local strategic needs assessment so that person centred local health, care and support services, based on good information about local needs, is available for people with Autism 	✓	Include Autism in the JSNA	Autism Implementation Group to include role of specialist services in developing approaches to support and needs planning	
<ul style="list-style-type: none"> I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnosis process 	✓	Review of the NHS diagnosis pathway (adults and children) and seek to ensure access to equitable services County Wide	Revised pathways and support approaches in place	
<ul style="list-style-type: none"> I want staff in health and social care services to understand that I have autism and how this affects me 	✓	Identify Autism champions in Health and Social Care services	Identify Autism Champions with wider partners	Review options for alternatives to face to face appointments (e.g GPs)
		Awareness raising and information programme		Consider introduction of Autism Passport
<ul style="list-style-type: none"> I want to know that my family can get help and support when they need it 	✓	Review Information, Advice & Guidance offer	Promote wider awareness raising of support available to Carers (e.g assessments, IA&G, respite etc)	
<ul style="list-style-type: none"> I want services and commissioners to understand how my Autism affects me 	✓	Include people with lived experience on the Autism Implementation Group	Review of Autism friendly approaches to Aging	

differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies		New Preparing for Adulthood process and SEND plans	Review of End of Life Care	
		Improve joint working between LAs and CCGs		
Outcomes to be achieved	Actions			
	Priority	By April 2021	By April 2022	Longer term
<ul style="list-style-type: none"> I want people to recognise my Autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging 		Analysis of effective interventions for people who are autistic with additional mental health problems	Development of quality standards in commissioned services	Review of housing opportunities
		Application of reasonable adjustments to Council and NHS services to improve access and support	Application of reasonable adjustments to other public services to improve access and support	
		Implement quality reviews using people with lived experience	Publicity and awareness campaign in Health care settings	Review of Autism awareness and specialist delivery in NHS and SCC contracted services
<ul style="list-style-type: none"> If I break the law, I want the criminal justice system to think about Autism and to know how to work well with other services 		Awareness raising and information for Law Enforcement agencies and their inclusion in the Autism Implementation Group	Partnership Review with Criminal Justice services	
3. Developing my skills and independence and working to the best of my abilities				

<ul style="list-style-type: none"> I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible 		<p>Awareness raising and information for services through web- based platforms and focus on SCC depth training</p>	<p>Publicity campaign as well as awareness raising</p>	
<ul style="list-style-type: none"> I want support to get a job and support from my employer to help me keep it 		<p>Partnership review with DWP and inclusion on Autism Implementation Group</p>	<p>Awareness raising for Employers in public, private and voluntary sectors</p>	<p>Review options for autism specific job coaching and buddy systems with partners (e.g. DWP)</p>
			<p>Monitoring of impact on employment outcomes.</p>	